DATA MANAGEMENT NEWS

New Website & Email

As announced to EBMT Members in October, the EBMT website has a new look. Information on the Registry, including downloads of the Data Collection forms, can now be found in the Data Management section on www.ebmt.org.
We also have new email addresses: please contact **registryhelpdesk@ebmt.org** from now on. The kcl.ac.uk Helpdesk email will be out of use from January**.** For a full list of our personal email addresses at the Registry please click here

Data Management Sessions: EBMT 2012 Preview

Pamela Welson
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Once again we are preparing an exciting line up of Education Sessions for Data Managers attending the EBMT Annual Meeting in Geneva (April 1-4 2012).

There will be training sessions on using the ProMISe system in the computer room:

- **Data Entry** session for **new users** on how to enter MED-A registrations
- **Data Retrieval** sessions for **experienced ProMISe users** focusing on obtaining data listings, frequencies and running reports
- **HLA data entry** session for **experienced users**
- **Med-B** for all users concentrating on the intricacies of Med-B data entry including missing data; follow ups; subsequent diagnoses and transplants with a practical Q&A session.

Please note that you will need to **enrol** for these sessions in advance using the congress registration form. Please note that your Institution may be charged for the full cost of the course (150 Euros) if you book a place but fail to show up on the day you are booked for. Facilities for **cancelling a booking** are available at the same link.

In addition, there will be a varied programme of educational, scientific and training sessions especially suited to Data Management professionals of all levels and interests. This year the sessions will include:

- Science: - Stem Cell Mobilisation, Antibodies, HLA
- Med B session: Acute Leukaemia (including ALL)
- Med A workshop session offering hints and tips for transplant registration & data entry
- JACIE- explanation and requirements for JACIE accreditation. By popular demand
- Data Quality –test your knowledge with the 1st Data Quality quiz!
- Follow up; Solid Tumours (with reference to Med-B); Paediatrics: Survivorship and long term follow up focusing on issues faced by patients.
- Presentations by Centres & National registries

Please visit the congress web page for the full programme , social events and registration. There will be something for everyone at EBMT 2012 and we encourage as many Data Managers as possible to attend. So book up now and join us in Geneva for this exciting programme!

SCETIDE Agreement

As part of the EBMT Registry's continuous commitment to facilitate the work of the centres, the Registry has entered into an agreement with **Stem Cell Transplant for Immuno Deficiencies in Europe (SCETIDE)**. The agreement allows SCETIDE to view relevant patient data submitted by the centre, so that the data only needs to be registered once. The agreement applies only to centres that have explicitly consented for their data to be accessible to SCETIDE. To share data on patients given HSCT for primary immune deficiencies and FELH, please see the CONSENT FORM

Thank you to all centres who have already been submitting their consent forms.

Disease Classification update

Aggressive NK cell leukaemia is actually a Lymphoma subclassification with code **182**. In our Disease list we incorrectly classified it as a Leukaemia, but this has now been corrected.

Common variable immune deficiency (CVID) is a type of primary immune deficiency that is not as severe as SCID but does get transplanted some times. It was already listed in the Med-A, and now we have added a code under the primary immune deficiency subclassification (code **100**).

The following 2 diseases have been classified in our list:
Granulocytic Sarcoma → Acute Leukaemia
Castelman's disease → Lymphoma

Data Collection Forms

1. Reminder: Lymphoproliferative disorders , if it happens after transplant, should be recorded as a secondary diagnosis and not as a complication as it was done in the past. (EBV presence does not need to be tested).

> **Did a secondary malignancy, lymphoproliferative or myeloproliferative disorder occur?**
> ☐ No ☐ Yes:
> Date of diagnosis: .... - .... - ....
>   *yyyy*   *mm*   *dd*
> Diagnosis: ....

2. The term "Engraftment" has been rephrased to "Recovery"

> **Absolute neutrophil count (ANC) recovery** *(engraftment)*
> *(Neutrophils $\geq 0.5 \times 10^9$ /L)*
> ☐ No: Date of last assessment: ....
> ☐ Yes: Date of ANC recovery: ....

3. When registering a Richter's syndrome using MED-B, you can now indicate the date of diagnosis of the preceding CLL if applicable.

> ☐ **Richter's syndrome:**
>   ☐ **CLL previously known: Date CLL diagnosis ....**

Changes to registration of Chimaerism

Earlier in the year we changed the MED-B form to enable registration of multiple chimaerism tests. Below are instructions for ProMISe users for cases involving multiple donors or cord blood units. (Please contact our Helpdesk with any queries).

With the current system it is not possible to use the same date for the chimaerism result for different donors. For this reason, when you have finished entering the results for one **chimaerism test** for the **1st donor**, ProMISe will offer you a new date which is the **original date + 1**, to allow you to enter the chimaerism test results for the **2nd donor**.

If the tests are done in different dates, there is no problem and you should use the real dates. Researchers will use the convention that data belonging to different donors, reported on dates differing only by one day, will be considered to have been all done on the 1st date reported.

Example: Patient has received 3 donations simultaneously
    PB from a related donor
    CBU-1
    CBU-2
A chimaerism test was done on the 2010/12/12, and the percentage of all donor cells were measured on that date.

a) You enter 2010/12/1**2** as the 1st date of chimaerism test
b) The data for the **related donor** is entered on the 2010/12/**12** record
c) The date 2010/12/**13** appears automatically in the navigation field **CM: New record index: graft assessment** inviting you to create that record if you want to enter data for another donor that was tested on the same date
d) You accept the date by hitting <Enter>, creating a record for 2010/12/1**3**
e) The data for the **CBU-1** is entered on the 2010/12/1**3** record
f) The date 2010/12/**14** appears automatically in the navigation field **CM: New record index: graft assessment** inviting you to create that record if you want to enter data for another donor that was tested on the same date
g) You accept the date by hitting <Enter>, creating a record for 2010/12/1**4**
h) The data for the **CBU-2** is entered on the 2010/12/1**4** record
i) The date 2010/12/**15** appears automatically in the navigation field **CM: New record index: graft assessment** inviting you to create that record if you want to enter data for another donor that was tested on the same date
j) You delete the date as you do not want to enter any more chimaerism tests and hit <Enter>